

**North Carolina Health Care Safety Net:  
Overcoming Barriers to Serving the Uninsured**

**Are Confidentiality Laws a Barrier to Forming Safety Net  
Collaborations to Provide Medical Care to the Uninsured?**

by

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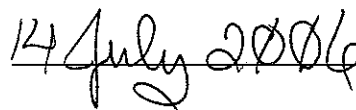
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## **Abstract**

In the United States, the health care safety net plays an important role in providing health care for uninsured individuals. Patient confidentiality is subject to both state and federal law and compliance with these laws is important to insure that safety net providers remain open and available to care for patients. The North Carolina Institute of Medicine suggests that in order to be efficient and provide quality care to patients, safety net providers must find ways to share information with others and collaborate on developing an integrated system of care.

Some North Carolina communities have managed to overcome barriers and develop collaborative networks that successfully serve the uninsured. The project described here was developed to understand how these successful collaborative networks have overcome barriers to collaboration with special attention to how they address the issues of sharing patient information and confidentiality. It is a secondary part of a larger project conducted by the North Carolina Institute of Medicine (NC IOM) Safety Net Advisory Council (SNAC).

Each of the four community collaboration projects approached patient confidentiality in slightly different ways, though some common themes emerged. The use of clinic-specific medical release of records forms and the use of legal assistance were the most common responses to address patient information sharing. Our findings seem to suggest that modalities for addressing confidentiality will be the same regardless of the level of knowledge regarding state confidentiality laws

The case studies presented here provide a list of many other barriers to collaboration between safety net providers beyond those of patient confidentiality. Resource limitations, physician recruitment and medications were

the only barriers that surfaced from multiple respondents and from multiple collaboration sites. Other obstacles appear to be unique to the individual collaborations. Our findings suggest that communities who are attempting to develop any type of collaboration need to consider carefully the available resources, physician / provider recruitment, and possible medication provisions in addition to questions surrounding the sharing of patient information.

Future research should move beyond barriers to collaboration and should address current and newly emerging barriers to serving communities so that the safety net collaborations are able to continue to provide care for the uninsured.

## Introduction

In the United States, the health care safety net plays an important role in providing health care for uninsured individuals. These organizations deliver a significant amount of health care to the uninsured, Medicaid or other vulnerable populations and often have a mission to offer services to patients regardless of their ability to pay. Some communities have successfully developed integrated systems of health care, however, most communities retain a fragmented safety net system of healthcare.<sup>1</sup>

In March/April 2005, the North Carolina Institute of Medicine (NC IOM) released the North Carolina Safety Net Task Force Report which contained recommendations to help strengthen and expand the ability of safety net providers to address the health care needs of the uninsured in their communities and in the state. The 28 recommendations were organized into four broad categories of concerns that safety net organizations should address. One of the four primary matters is “Strengthening safety net integration and collaboration efforts”. The report suggested that safety net organizations need to work together to maximize the use of limited resources to maintain and expand care to the uninsured.<sup>2,3</sup>

Unfortunately, strengthening integration and collaboration between safety net organizations may pose many challenges. The NC IOM Safety Net Task Force Report also identified several potential impediments to health care collaborative networks. These include variables such as: information sharing and confidentiality laws; inclusiveness defined as the sense (or absence) of shared responsibility; feelings of relative advantage; professional economics; fear of unknown; adequate physician representation; trust; competition for non-economic resources; lack of recognition; and payment / cost avoidance.<sup>2,3</sup>

In an effort to understand the function, role, and barriers to safety net collaborations, I turned to the published literature. Initially, I searched for published data on the existing safety net as it functions today. Next, I conducted a review of recent literature on existing models of integration and collaboration between safety net organizations. Using the search terms, “safety net collaboration”, I searched the Medline database for information on safety net collaborative networks. This yielded fewer than 40 publications on the topic. To expand the search, I included publications that seemed to focus on any aspect of health care collaboration – not necessarily limited to the safety net. The expanded search included publications that discussed safety net collaborative networks, community collaborations, inter-organizational networks, and health care networks. After identifying the publications that discussed collaborative networks, I further expanded the search by using the ‘Related Articles’ link in Medline. In addition, as I identified pertinent publications, I reviewed the references from these documents for additional documents.

Rather than focusing on barriers to collaborative formation, much of the literature addresses the effectiveness of health care collaborative networks<sup>4</sup> often for a specific disease state<sup>5</sup> or populations.<sup>6, 7</sup> Ultimately, I discovered that there is little information available on barriers to integrated safety net collaborations - especially with regard to sharing patient information and matters of patient information confidentiality. Thus, we sought a method of investigating this information on our own by performing community case studies. This paper will present data on North Carolina communities that have successfully navigated the collaboration process and overcome the obstacles associated with such integration of the safety net health care system. Specifically, we will focus on the

problem of sharing patient information between various providers within the safety net organization.

## **Background**

In 2004, 45.8 million people in the United States were without health insurance; 1.3 million of those individuals lived in North Carolina.<sup>8</sup> Many of the uninsured in North Carolina have incomes less than 200% of the federal poverty guidelines making it difficult for them to pay for medical services. Uninsured people with low incomes are less likely to have a regular source of care and more likely to delay or forgo necessary medical care than are individuals with health insurance.<sup>2, 3</sup> When the uninsured do seek care, they are often sicker and have worse health outcomes than do persons with insurance.<sup>3</sup>

Beyond the individual effect on the uninsured person and his or her family, lack of health insurance can also lead to significant societal effects, including several factors that impair children's, ability to learn, decreased worker productivity and even unfavorable financial outcomes for the organizations and providers who attempt to provide care for the uninsured. As these examples make clear, lack of health insurance has ripple effects far beyond the harm it does to the individual uninsured person; its consequences are burdensome for health care system and for society as a whole.<sup>3</sup>

One response to the challenge of widespread uninsurance has been the establishment of the health care safety net. Organizations in the safety net deliver a significant amount of health care to the uninsured, Medicaid or other vulnerable populations and often have a mission to offer services to patients regardless of their ability to pay. Usually safety net organizations will find methods to make services affordable – including providing services for free or on

a sliding-fee scale basis.<sup>3</sup> In North Carolina, the safety net consists of a variety of organizations, including federally qualified health centers, state funded rural health centers, hospitals, local health departments, free clinics, school based clinics and more. Many private health care providers will also provide care to the uninsured, though they may not offer sliding scale services.<sup>3</sup> The health care safety net is truly a “patchwork” of organizations united by the goal of serving the uninsured.

The 2000 Institute of Medicine (IOM) Report: *America’s Health Care Safety Net* evaluated the national safety net resources and concluded that the safety net is intact, but fragile; despite the lack of true financial security, the report found that the health care safety net has managed to survive and continue to provide care to the uninsured.<sup>1</sup> However, recently changing social conditions threaten the integrity of the safety net. Examples include: increasing numbers of uninsured individuals; increasing use of managed care including Medicaid managed care; declining Medicaid enrollment; increased competition for Medicaid patients; decreasing revenues for traditional Medicaid patients; declining coverage for immigrants; declining federal subsidies for primary care; increasing burden of uncompensated care for all providers; less funding for uncompensated care and the growing unwillingness of private providers to provide charity care.<sup>9</sup> North Carolina, has limited funding available to subsidize care for the uninsured; what is available is not sufficient to cover all costs and is often not targeted toward the safety net organizations that provide the greatest amount of care to the uninsured.<sup>2,3</sup> Such a fiscal environment significantly impairs the ability to provide health care to the uninsured.

In 2004-2005, the North Carolina Institute of Medicine (NC IOM) established a Healthcare Safety Net Task Force to examine and make recommendations

regarding the existing safety net structure in North Carolina. According to the NC IOM, the state has a wide array of safety net organizations disbursed throughout the state, but, the existence of safety net resources within a community did not guarantee that they are sufficient to meet all of the health care needs of that community.<sup>2,3</sup> The NC IOM report compared the number of people receiving health care from the existing safety net to the number of uninsured in a particular area and determined that only about 25% of all the uninsured throughout the state receive primary care services from safety net providers. Of course, this percentage varies between counties and may be higher or lower depending on the community. Nevertheless, the fact that approximately three fourths of our uninsured residents do not receive primary care from safety net providers suggests that the safety net is not quite sufficient to meet the needs of the uninsured in North Carolina. Access to pharmaceuticals, specialty care, behavioral health care and dental services also appears to be lacking in many communities.<sup>3</sup>

The NC IOM 2005 Safety Net Task Force Report contained recommendations to help strengthen and expand the ability of safety net providers to address the health care needs of the uninsured in their communities and in the state. The recommendations were organized into four categories of issues facing safety net organizations. One of the four primary issues is “Strengthening safety net integration and collaboration efforts”. The report suggested that safety net organizations will need to work together to maximize the use of limited resources to maintain and hopefully expand care to the uninsured.<sup>23</sup>

Collaborative networks generally consist of groups of health, human service, and other organizations concerned with community health. These organizations



are often clustered in the same geographic area and share resources, clients and information. Typically, the focus of the collaboration is to address a critical health need in the community such as medical care for the uninsured. Organizations providing many different types of services are able to coordinate their efforts so that resources, information and expertise can be widely and efficiently shared.<sup>5</sup>

Some communities have developed successful integrated systems of health care, but, most communities retain a fragmented safety net system of healthcare.<sup>1</sup> The fragmentation may be due in part to what Bolland and Wilson describe as the *paradox of success*. With increasing public awareness of health issues, communities will often have a proliferation of organizations seeking to address health care concerns. As more community agencies arise to address local needs they must compete for clients and resources and are less able to coordinate and work toward the same goal.<sup>7</sup> When allowed to persist, this trend can lead to instability in provision of health care services resulting in the fragmented care that we currently see in our safety net. Biel notes that as conditions in the health care environment become more turbulent and uncertain, health care organizations often seek to become more coordinated in service provision.<sup>10</sup> Given the desire for more collaboration among safety net providers, the taskforce recommendation to strengthen integration and collaboration is quite timely.

In order to reach this goal, we must have a good understanding of what hinders community collaborative efforts so that communities can devise ways to overcome these obstacles. In general, little published information specifically explores barriers to collaborative efforts. The 2005 NC IOM Safety Net Task Force Report identified several potential impediments to health care collaborative networks. These included concerns about sharing patient information and

confidentiality laws; inclusiveness defined as the sense (or absence) of shared responsibility; feelings of relative advantage; professional economics; fear of the unknown; adequate physician representation; trust; competition for non-economic resources; lack of recognition; and payment/cost avoidance.<sup>2, 3</sup>

In other research, Taylor, Cunningham, and McKenzie present additional barriers to collaborative networks from a slightly different standpoint. First, they introduce four models of community collaboration that may arise in a community as efforts are made to provide health care for the uninsured. *Managed care safety-net models* are exemplified in communities where the existing safety net organizes to coordinate better care for the uninsured. *Donated care models* are typically seen in communities who already have a strong history of charity care. Participating community physicians will agree to see a certain number of patients or allow a certain number of visits pro bono each year. This model often provides structure and encourages greater participation in existing charity care resources. *Discounted care collaborative models* are a variation of the donated care model in that participating providers agree to provide certain health care services at a discounted rate to individuals who purchase a discount card. Finally, a newer development among collaborative models is the *limited-benefit coverage model*. This strategy which provides limited insurance benefit coverage to participants rather than focusing on improving access sites for the uninsured.<sup>11</sup>

Taylor, Cunningham, and McKenzie then explore the strengths and a few barriers faced by communities trying to develop an integrated safety net organization. Some barriers, such as limited resources for outreach, little capacity to serve, and lack of financial means, are common to many different integration models. Other obstacles may be more specific to a particular model.

For example, donated services models are more likely to face difficulties engaging community partners in the program, while limited-benefit programs may find little demand for the services they offer.<sup>11</sup>

Bolland and Wilson discuss collaboration in the form of inter-organizational networks that they define as clusters of groups of agencies centered on specific needs where coordinated care is provided through strong connections between the participating agencies.<sup>7</sup> This system of inter-organizational networks was originally introduced in earlier literature by Emery and Trist,<sup>7</sup> who cited barriers such as (1) philosophical barriers between health and social service agencies; (2) geographical barriers between agencies based on socioeconomic class; (3) geographical barriers between agencies based on rural or urban client; and (4) legal barriers between agencies serving clients of different ages.<sup>7</sup>

Even fewer studies specifically address sharing of patient information or confidentiality laws as a significant barrier to integrated care by safety net providers. The NC IOM Task Force Report is essentially the only document that specifically mentions these patient information and confidentiality concerns. Bolland touches on some legal issues, but not confidentiality laws. No source delves deeply into the question of how confidentiality had the potential to hinder the formation of collaborative networks.

All health care providers will share patient information with another provider at some point during their careers and all must deal with the need to maintain patient confidentiality. The need for confidentiality may present greater challenges for safety net providers, because uninsured patients may often seek care from multiple providers who are unaware of one another. Patient confidentiality is subject to both state and federal law; safety net providers must comply with these laws if their doors are to remain open and if they are to retain

the ability to collaborate with other providers. Failure to comply with confidentiality laws, either because of lack of knowledge of the laws, unclear interpretation or willful violation of them, can prevent the formation of collaborative networks, ultimately harming the health of the uninsured citizens in that community. The NC IOM report suggests that in order to be efficient and provide quality care to patients, safety net providers must find ways to share information with others and collaborate on developing an integrated system of care<sup>2,3</sup> while remaining in compliance with the letter and spirit of patient confidentiality laws.

In order to begin this process of building networks that will comply with confidentiality requirements, we must first understand the federal and state laws that govern patient confidentiality. The federal Health Insurance Portability and Accountability Act of 1996 (HIPAA) was originally created to serve a number of purposes surrounding health insurance and health care delivery. Included within the act is a section entitled 'Administrative Simplification' that requires the US Department of Health and Human Services (DHHS) to develop a series of rules intended to standardize the electronic exchange of health care information. This allows information sharing for certain financial and administrative transactions such as insurance claim transactions, health plan enrollment, health care payment and injury reporting. HIPAA also includes a section requiring DHHS to develop regulations governing security and privacy of health information. This section includes information on specific measures to protect the confidentiality of patient information such as requiring providers to distribute notices of privacy practices and establish written privacy policies and procedures.<sup>2, 12-14</sup>

In response to HIPAA, the US Department of Health and Human Services issued the *Standards for Privacy of Individually Identifiable Health Information*

(The Privacy Rule), established, a national guideline for the protection of health information for the first time. One primary goal of the Privacy Rule is to insure that health information is protected while allowing the flow of information necessary to provide and promote high quality health care and to protect the public's health and well being. The standards of the Privacy Rule address the use and disclosure of an individuals' health information by the organizations which are subject to the Privacy Rule. In addition, the Privacy Rule presents standards for privacy rights for individuals to understand and control how their health information is used.<sup>14, 15</sup>

The Privacy Rule protects all "individually identifiable health information" in any form of media, electronic, paper or oral. The Privacy Rule refers to this information as 'Protected Health Information' (PHI). PHI is information, including any demographic information, collected from an individual that relates to a past, present; or future physical or mental health condition; the provision of health care to the individual; or the past, present, or future payment for the provision of health care. PHI is any information that identifies the individual or for which there is a reasonable basis to believe it can be used to identify the individual. It includes many common identifiers such as name, address, date of birth, social security number, etc.

The HIPAA Administrative Simplification rules as well as the DHHS Privacy Rules apply to health plans<sup>i</sup>, health care clearinghouses<sup>ii</sup> and to any health care

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<sup>i</sup> 'Health plan' refers to an individual or group plan that provides or pays the cost of medical care as defined in section 2791 of the Public Health Service Act. This includes Medicare, Medicaid, health maintenance organizations (HMOs), long-term care insurers, employer-sponsored group health plans and other insurers of health, dental, vision and prescription drugs.<sup>12, 15</sup>

<sup>ii</sup> 'Health care clearinghouse' refers to a public or private entity (such as a billing company) that processes or facilitates the processing of nonstandard data elements of health information into standard data elements.<sup>12, 15</sup>

provider<sup>iii</sup> who transmits information in electronic form in connection with such financial and administrative transactions mentioned previously. These individuals and organizations are referred to as “covered entities”. A covered entity may not use or disclose “individually identifiable health information” except (1) as permitted or required by the Privacy Rule or (2) as the individual (or personal representative) who is the subject of the information authorizes in writing. Disclosure of health information is required in only two situations: (1) when an individual requests access to his / her health information and (2) when DHHS requests the information for a compliance investigation, review or enforcement action. Covered entities are permitted (but not required) to disclose health information without authorization in a variety of other situations, including: (a) to the individual (without his or her formal request); (b) treatment<sup>iv</sup>, payment<sup>v</sup> and health care operations<sup>vi</sup> purposes (c) situations in which the individual is given an informal opportunity to agree or object (such as in the emergency room); (d) incident to another permitted use and disclosure; (e) public interest and benefit activities, such as public health, research, law enforcement, and disaster relief.<sup>14, 15</sup>

As we previously mentioned, The Privacy Rule was the first set of national standards for confidentiality and sharing of health information. However, states

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<sup>iii</sup> The phrase ‘health care provider’ includes providers of services (i.e., institutional providers such as hospitals), providers of medical or other health services (such as physicians, dentists, etc.), and any other person furnishing health care services or supplies.<sup>12, 15</sup>

<sup>iv</sup> Treatment refers to the provision, coordination, or management of health care and related services for an individual by one or more health care providers, including consultation between providers regarding a patient and referral of a patient by one provider to another.<sup>15</sup>

<sup>v</sup> Payment includes all activities of a health plan to obtain premiums, determine or fulfill responsibilities for coverage and provision of benefits, and furnish or obtain reimbursement for health care delivered to an individual and activities of a health care provider to obtain payment or be reimbursed for the provision of health care to an individual.<sup>15</sup>

<sup>vi</sup> Health care operations include activities such as quality assessment and improvement, competency assurance activities, medical reviews, etc.<sup>15</sup>

also implement laws to govern sharing of health information within their respective borders. Thus, health care providers must consider both the HIPAA Privacy Rules and their respective state laws when addressing patient confidentiality and health information sharing.

In general, it seems that state laws can fall into one of four categories in relation to the HIPAA Privacy Rules, the law is (1) not contrary<sup>vii</sup> to the Privacy Rule; (2) contrary to and less stringent than the Privacy Rule; (3) contrary to the Privacy Rule but exempted from preemption; or (4) contrary to and more stringent than the Privacy Rule.<sup>16</sup> If the state law falls into the first category and is not contrary to the Privacy Rule then adherence to the law does not interfere with adherence to the Privacy Rule. The state legislature may support the Privacy Rule or it may simply apply in a different circumstance or for a different group than those described in the Privacy Rule. In this instance, the state law is not preempted and health care providers should comply with both the federal and state requirements.

The other three categories deal with state laws that are contrary to the Privacy Rule and present situations where health care providers may struggle with legal compliance. Of these three, state law that is contrary to the Privacy Rule and less stringent offers perhaps the least complicated interpretation. The general rule is that state laws which are contrary to the Privacy Rule are preempted by the federal requirements. Thus, health care providers who encounter this type of state legislation should comply with the Privacy Rule rather than the state statutes. However, keep in mind that this only applies for the

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<sup>vii</sup> Contrary means that it would be impossible for a covered entity to comply with both the State and federal requirements, or that the provision of State law is an obstacle to accomplishing the full purposes and objectives of the Administrative Simplification provisions of HIPAA.<sup>14, 15, 17</sup>

covered entities (health plan, health care clearinghouse, and health care providers) that we discussed earlier. Therefore, the state can enforce a state confidentiality law for a non-(HIPAA) covered entity that would be unenforceable for a covered entity subject to the federal regulations. This distinction will be important later as we discuss how the laws interact in collaborative health care networks.

The third classification of state – HIPAA interaction exists because of provisions set forth in the Privacy Rule which offers three exemptions to the general rule of federal preemption over state law. This occurs when the state law: (1) offers more privacy protection than the Privacy Rule (discussed below); (2) provides for reporting of health data for public health surveillance, investigation, or intervention; and (3) requires health plan to report health information, such as for financial audits.<sup>14, 15, 17</sup> As a result, a state law may be contrary to the Privacy Rule yet qualify for exemption from preemption. However, this does not mean that health care providers can disregard the Privacy Rule. Instead this indicates that providers cannot disregard the state legislation in favor of compliance with the Privacy Rule. In this instance, health care providers should comply with *both* the Privacy Rule and the state legislature.

State laws that are more stringent than the Privacy Rule simply offer more privacy protection for individuals' health information. For example a state law that restricts the disclosure of patient information in a setting where the Privacy Rule would allow it is an example of a more stringent law. These laws can address various components of the Privacy Rule, such as greater rights of access for the individual to whom the PHI belongs, more stringent requirements on the information presented on consent forms so that providers must provide



additional information to patients about their privacy practices, or stricter requirements for recordkeeping or reporting.<sup>17</sup> In these situations, health care providers are not permitted to disregard state legislation in favor of compliance with the Privacy Rule and should comply with *both* HIPAA and the state law.<sup>14, 15,</sup>

<sup>17</sup> Of course, in this situation, compliance with the state law may often result in concomitant compliance with the Privacy Rule. Ultimately, states can provide for additional protection of patient health care information should they choose to do so.

In North Carolina, the state confidentiality laws regarding sharing patient information between health care organizations presents a challenge, even before we consider their interaction with the Privacy Rule. To begin with, North Carolina has a substantial number of laws (including general statutes (GSs), regulations, and case law) that address confidentiality of health information. In addition, NC confidentiality laws can be difficult to locate. There is no specific chapter containing all laws for handling health information; rather, confidentiality laws are interspersed throughout the general statutes. For example, within Chapter 130A of the NC Statutes entitled Public Health there are multiple laws that focus on some element of confidentiality or handling of patient health information. These include Article 1B<sup>viii</sup>, Article 5<sup>ix</sup>, Article 6<sup>x</sup>, and Article 7<sup>xi</sup> among several others. Additionally, confidentiality legislation can be located in other chapters of the NC Statutes such as the Mental Health, Developmental Disabilities and Substance Abuse Act (GS122C), the section on Health Care Facilities and Services (GS131E), as well as the section on State Departments,

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<sup>viii</sup> Address confidentiality as it relates to public health authorities.

<sup>ix</sup> Address confidentiality with regard to Maternal and Child health

<sup>x</sup> Address confidentiality with regard to Birth defects

<sup>xi</sup> Address confidentiality with regard to Communicable diseases

Institutions and Commissions(GS143).<sup>18</sup> Health care and service providers with limited time and resources – such as those who often work with safety net organizations – may find it challenging to navigate through the state legislature to determine what laws are relevant for their circumstances.

Interpretation of North Carolina confidentiality laws presents another source of ambiguity for health care providers. Unfortunately, the objective of a particular law is not always perfectly clear. Interpretation may vary depending on the individual who is reading it. For example, GS8-53 addresses the use of communications between a physician and a patient during judicial proceedings. It establishes physician-patient privilege which dictates that during judicial proceedings, a physician shall not disclose records of patients or testify regarding any information acquired while attending to the patient in a professional role.<sup>18, 19</sup> Of course, there are some exceptions which include authorization by the patient (or representative) or a mandate from a resident or presiding judge. Some attorneys interpret this statute as a general rule of confidentiality and advise their health professional clients to apply this rule to all dealings involving patient health information.<sup>19</sup> Other attorneys argue that this is an incorrect interpretation because (1) the language of the law refers to districts and a presiding judge, (2) the law is written in the section of the legislation which deals things that a witness may testify; and (3) the creation of additional confidentiality laws after GS8-53 was passed argues against it being a comprehensive confidentiality law.<sup>19</sup>

Considering the ambiguous wording and the large number and variety of statutes to address patient confidentiality, it is easy to understand why the North Carolina confidentiality laws can quickly become confusing. It can be difficult to determine what is necessary for compliance. Health care providers must first determine the applicable statute covering the circumstances in which they

practice, then generate or obtain an acceptable (and hopefully accurate) interpretation before they ever begin to apply the law to their practice. But the situation becomes even more complex when we begin to try to integrate the state law with the federal Privacy Rule.

Perhaps a simple way to understand the interaction is to look at the state-federal interaction in stages. First, health care or health service providers ask the question, “Am I a considered a covered entity under the Privacy Regulation?”. If the answer to this is “No”, then they do not need to comply with the Privacy Rules and must only be concerned with state laws. If the answer is “Yes”, then they must determine to which state laws they are subject and whether those laws are preempted by the Privacy Rule, i.e., whether they are contrary and less stringent or contrary and not qualified for exemption from preemption. If the laws are preempted by the Privacy Rule, then the providers should only be concerned about compliance with the Privacy Rule. It is important to note that very few state laws are actually preempted by the Privacy Rule.<sup>16</sup> This means that providers are still subject to the state legislation and could indeed be penalized for noncompliance with state confidentiality requirements. However, if the law is not preempted, or the law is exempt from preemption then the provider must comply with both the Privacy Rule and the state law. It is not surprising that safety net providers may be ill-prepared to make such intricate determinations.

When we consider the process in small stages, it seems somewhat more manageable; but we must remember that for the example above, we are only thinking from the viewpoint of a single provider. A single safety net provider may be able to work through the model and determine which law to address. However, when providers begin to collaborate and attempt to integrate health

care service provision, the situation again becomes more complicated. Providers who are “covered entities” will need to share health information with providers who are not, and vice versa. In addition, one organization may be subject to a state law that covers health departments while another may be subject to a law that covers the state trauma system of care. One organization may be subject to a state law which is preempted by the Privacy Rules while another may be obligated to comply with both a state law and the HIPAA Privacy Rule. Each of these providers has different compliance requirements yet wish to integrate their services to improve care for the uninsured. The HIPAA Privacy Rule offers some assistance with this matter through two possible methods, Business Associates and Organized Health Care Arrangement (OHCA).

A “business associate” is a person or organization that performs certain functions or activities on behalf of a covered entity or provides certain services to a covered entity that involve the use or disclosure of protected health information. Business associates are not members of the covered entities workforce, but a covered entity can be the business associate of another covered entity. Services performed by business associates on behalf of the covered entity can include claims processing, data analysis, quality assurance, and others. Business associates who provide services to the covered entity that require disclosure of PHI are limited to legal, actuarial, accounting, consulting, data aggregation, management, administrative, accreditation, or financial services.<sup>13-15</sup> Once business associates are identified, a covered entity may only disclose PHI or allow the business associate to create or receive PHI on its behalf if the covered entity obtains “satisfactory assurance” that the business associate will appropriately safeguard the information.<sup>13</sup> This is often accomplished through a business associate contract in which the covered entity must impose specified

written safeguards on the PHI used or disclosed by its business associates.<sup>15</sup> In the context of a safety net collaboration, a data processor who processes dummy insurance claims that contain personal health information, would be a business associate of the covered entities in that collaboration.

An Organized Health Care Arrangement (OHCA) is an arrangement or relationship that allows two or more legally separate covered entities who participate in joint activities to share protected health information about their patients in order to manage and benefit their joint operations. To qualify as an OHCA, the covered entities must be clinically or operationally integrated and share protected health information. Patients should expect that these organizations are integrated and will share health information to manage their operations. For example, an OHCA might be established in a hospital setting where the hospital and the physician with medical staff privileges at the hospital together provide treatment to a hospitalized patient and need to be able to share PHI to treat the patient and to improve hospital operations.<sup>14, 20</sup> In safety net collaborations, hospitals may allow community physicians the use of their facilities at no charge when they are treating patients within the collaboration. As in the previous example, the hospital and the community safety net physician could form an OHCA that would permit them to use a single consent form and share PHI in accordance with the Privacy Rule. .

Both the concepts of business associates and OHCA offer some guidance for safety net providers who desire to form collaborative networks yet maintain patient confidentiality. The concept of the business associates was created by DHHS to insure that anytime PHI was used or disclosed by or on behalf of a covered entity to a non-covered entity, the Privacy Rules would continue to apply and therefore continue to protect the individual's health information.<sup>13</sup> If we

consider the setting of integrated safety net health care providers consisting of both covered and non-covered entities, then the business associate provision requires that the non-covered entities comply with the Privacy Rule as well – provided they qualify as a business associate. In general, , the Privacy Rule allows covered entities to share PHI for treatment, payment and healthcare operations<sup>xii</sup>; however each covered entity who will share the PHI for health care operations must have a separate and individual relationship with the patient. Under the auspices of the OHCA, covered entities that have no relationship with a patient are permitted access to PHI of patients for treatment, payment and healthcare operations – such as quality assurance or utilization review – without a business associate agreement. In addition, the covered entities within the OHCA may use a single Notice of Privacy Practices rather than several individual forms for each entity.<sup>20</sup> On the other hand, health care providers may be averse to establishing an OCHA because the integration requires that they be known as integrated entity.<sup>16</sup> Some safety net providers may prefer a more informal integrated network.

While the business associates and OHCA designations permit some integration of services, and fairly clearly mandate compliance with federal privacy rules, no such comparable designations exist in North Carolina state confidentiality laws, nor is there any clear-cut way to determine how the state and federal laws interact once organizations integrate their services. Collaboration between safety net providers is crucial to improving health care services to the uninsured but how can providers insure that they are within all federal and state legal guidelines? The NC IOM Task Force report notes that providers are committed to protecting the privacy of their patients' health information and want

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<sup>xii</sup> See above footnotes iv, v, vi

to comply with all applicable laws, but have difficulty understanding the full scope of North Carolina laws.<sup>2,3</sup> Thus, it may be difficult for health care safety net providers to integrate community resources and services for the uninsured while also insuring compliance with all regulations.

Yet, some North Carolina communities have managed to overcome this obstacle and develop collaborative networks that successfully serve the uninsured. The project reported on in this paper, was developed to understand how these successful networks have overcome barriers to their collaboration with special attention to how they address the issues of sharing patient information and confidentiality. This research is a secondary part of a larger project conducted by the North Carolina Institute of Medicine (NC IOM) Safety Net Advisory Council (SNAC). The council was created on the recommendation of the NC Safety Net Task Force to encourage state and local level safety net collaboration and to monitor the implementation of the Healthcare Safety Net Task Force recommendations, which included strengthening safety net integration and collaboration efforts. The research project required contacting local communities to find out more about their community safety net collaborations, what they perceived to be the barriers to collaboration and integration, and how these communities overcame the barriers they faced. The goal of the primary research was to identify what works for forming collaborations and then use this information to develop a technical assistance manual to help other communities expand care to the uninsured through safety net collaboration. Secondly, this paper presents data on communities that have successfully navigated the collaboration process and explore what barriers they dealt with when integrating the safety net health care system. Specifically, we will focus on

the problem of sharing patient information between various providers within the safety net organization.

## **Methods**

The study, the consent materials, and the interview protocol were reviewed by and approved by the Institutional Review Board of the UNC School of Public Health.

### *Community Participants*

The Safety Net Advisory Council developed a list of eleven communities in North Carolina on which to focus the interviews. Each community had an established medical safety net that was integrated between multiple safety net organizations in the community. Various graduate program assistants were assigned to conduct interview with key informants in the eleven communities. The eleven communities were assigned to various graduate program assistants to conduct the interviews. I specifically interviewed four communities, to be known in this paper as, A, B, C, and D, from different parts of North Carolina. I conducted eight interviews with nine representatives of the four safety net collaborative organizations. One community chose to conduct a single interview with two key informants present. In other communities interviews were conducted individually with each key informant. These representatives were identified as primary contacts by members of the Safety Net Advisory Council. Respondents included representatives of community and migrant health centers, free clinics, local health departments, state-funded rural health clinics, free clinics, hospital outpatient clinics, Project Access sites, Healthy Community Access Programs (HCAP) and other nonprofit organizations that provide health care services to the uninsured. In addition, the contact list included some



individuals whose position was explicitly that managing the community collaboration that had been established. Often, the representative had been involved in the collaboration early in its development. The number of key informant interviews for each community was determined by (1) the number of contacts that were identified for that community and (2) the number of individuals who were willing to participate in the project.

### *Materials*

We developed a protocol for conducting the interviews that all of the graduate students were to follow. The consent script (Appendix A) was used for initial contact by telephone and was designed to introduce the project to each contact person, insure that the contact person was knowledgeable about the collaboration in question, and then obtain permission to conduct the interview. In addition, the consent script provided an opportunity for each representative to provide the name of an alternative contact if he / she felt that someone else could be an informed respondent for that community's interview.

When obtaining consent, we also sent – via email or fax – a copy of a fact sheet containing information about the project (Appendix B). This sheet informed participants about the project by answering questions such as who is conducting the study, the study's purpose, the role of the participants, risks and benefits, and the like. In addition, we provided contact information for the project directors so that participants could contact them at any time with further questions.

All interviews were conducted using a semi-structured interview guide (Appendix C) developed specifically for this project. This guide contained three focal sections. The first section focused on obtaining background information on the collaborative, including the history of its development, the organizations involved, the types of services provided and the types of patients served. The

next section was designed to elicit information on any barriers respondents perceived to have emerged in developing and maintaining the collaboration. It focused on determining what factors contributed to the success of the collaboration and what factors would be important for the development of a similar collaboration in another location. This section also contained specific probes into the question of confidentiality of patient records and how it was addressed for the multiple providers within the collaboration. The final section collected information on a variety of measurable outcomes from the collaboration. It elicited data on numbers of uninsured served, patient satisfaction and health status outcomes such as hospitalizations or other clinical indicators.

*Procedure:*

After obtaining IRB approval for this project, we began contacting representatives from the list provided by the SNAC. Many of these individuals were initially contacted either via telephone or email. We did not use a standardized protocol for initiating contact via email, however, interviewers were required to follow the structure of the telephone consent script to the extent possible. After consent was obtained, we scheduled interviews based on the availability of the respondent. At the appointed time, we conducted each interview via telephone using the interview questionnaire guide. During the interview, the interviewer typed in responses to the questions as they were given. We would have preferred to record each interview session; unfortunately, the telephones used for the interviews were not equipped with recording devices.

After each interview session, the interviewer reviewed and edited the typed summary for correctness. These summaries were then sent to a second reviewer at the NC IOM office where they were assessed for clarity and

comprehension. Both reviewers were able to highlight areas that required some clarification. The interviewer merged and consolidated the edits into a new document and returned the transcript to the respective representative with a request that he or she review the summary transcript for correctness and clarity. The organizational representative was permitted to make any changes that he or she felt necessary to convey the message he or she had intended to impart. After we received the interview transcript from the organizational representative, the interviewer conducted a final read to assess any new changes to the document and insure that all points of clarification had been addressed. This version was logged as the final version of the transcript and a copy was sent to the President of the NC IOM. The final version of the interview transcript was also converted to a text summary for future use (Appendix D).

#### *Analysis:*

Though the primary project solicited interviews from eleven community collaborations, we use the results from four of those organizations<sup>xiii</sup> for this analysis. The purpose of this project was to investigate barriers to collaborative formation; thus, the analysis primarily focused on the responses from the section of the interview that asked questions regarding those issues. To interpret the data, we identified the information most relevant to our research question then organized the responses base on a method described by Miller.<sup>21</sup> We developed a table to catalog the responses for each question in this section,. Each row in the table contained a particular response to the question along with a code that identified the source interview from which it came. Some responses had multiple source identifiers because they were given by multiple respondents. Once this

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<sup>xiii</sup> These were the interviews actually conducted by the author

task was completed, we were able to identify common themes or concepts that emerged in response to the interview questions.

## Findings

Table 1, shows the varying mechanisms each community used to address confidentiality. The left-hand column, headed "ID," lists which communities gave that particular response. The letter corresponds with the particular community (A,B,C, or D) and the number corresponds with a particular key informant. For example, key informant number 2 from community B would be ID B-2.

**Table 1** - Responses that address the question, "How do you address patient confidentiality issues?" – grouped by common themes.

ID	Address Confidentiality
A-1, A-2, A-3, B-1,	Medical Release of Records forms (separate for each clinic)
D-1, D-2, C-1, B-2	Used legal assistance to develop forms (lawyers or state consultants)
A-2, B-2, D-2	Collaborative administrators share enrollment information but not medical information
D-1, D-2, C-1	Share HIPAA documentation & consent form (all partners listed on consent form)
A-1, B-2	HIPAA partner agreement; Confidentiality agreements

The use of a medical release of records form and the use of legal assistance to develop compliance forms appear to be the most common methods of dealing with sharing patient information by the communities involved in our project. Four respondents from three community sites (B, C, and D) address the use of legal assistance through lawyers or state consultants. The use of medical Release of

Records forms was also mentioned by four respondents who represented two community sites (A and B). Three communities, represented by three respondents, also choose to share patient enrollment information but refrain from sharing medical information as a method of dealing with patient confidentiality.

**Table 2** – Responses to the question: Did you have any barriers to collaboration that you needed to overcome?

ID	Barriers
A-2, D-1, D-2	Funding / resources; writing grants
A-3, B-1, B-2	Recruiting physicians
A-2, B-1	Medications
D-1, D-2	Hiring of staff; finding people & getting them trained
D-1	Sharing patient information
A-1	Recognition (who receives it)
A-3	Recruiting hospital
B-2	Translation services
B-2	High rate of ER use
A-1	Guardedness of funding / resources
D-1	Legal issue of sharing patient information
D-2	Feeling of helplessness within the community
D-2	Continuity
C-1	Distribution of deficit programming

Overall, as Table 2 makes clear, many of the barriers that emerged were unique to the particular collaboration and even to a particular respondent. However, four kinds of responses did surface from multiple respondents. “Funding/Resources” and “physician recruitment” were mentioned as barriers by

three different respondents representing two different collaborations. Two different respondents mentioned “medications” and “hiring staff” as barriers; the representatives who mentioned medications were speaking for two different collaborative networks; hiring concerns were mentioned by two different people, but those people came from the same collaborative network. Interestingly, “patient confidentiality” arose unprompted as a barrier in only one interview.

## **Discussion and Conclusion**

Each of the four community collaboration projects approached patient confidentiality in slightly different ways, though some common themes emerged. The use of clinic-specific medical Release of Records forms and the use of legal assistance to develop forms were the communities’ most common solutions. In some ways, each method allows the collaborative organizational leaders to avoid direct entanglement in state and federal laws. The medical Release of Records forms circumvent the legal issues by providing legal consent for sharing patient medical records. Collaborative networks that use them do not have to be concerned with deciphering what part of patient health information can be shared between organizations. Of note, the use of a consent form complies with the HIPAA Privacy rule and North Carolina General Statutes, GS8-53 and GS131E-310. Because we do not know the prior level of legal expertise of the collaborative partners, we do not know whether this choice was incidental or intentional.

The use of legal consultants is perhaps a clear attempt on the part of the collaborative networks to solve the problem of integrating state and federal laws. This method permits collaborative networks to take advantage of appropriate expertise to insure that any forms or policies comply with federal and state laws.

Administrators of safety net organizations do not have to be directly concerned or familiar with the intricacies of confidentiality law; yet, their reliance on recognizably expert advisors helps prevent such laws from becoming barriers health care integration and potentially hindering the care for the uninsured. Historically, medical consent forms have been individually prepared for a specific facility. Thus, when providers began to form collaborations, perhaps it was simply easier to leave the individual forms in place. However, it is interesting to note that three of the four respondents who indicated that they used legal assistance also mentioned that they used a single shared consent form for collaborative providers (Example in Appendix E). Perhaps this indicates that collaborations that use such shared forms are taking a more active role in addressing patient confidentiality and are recognizing a more efficient means to comply with state and federal regulations. The use of shared consent forms may also suggest that those collaborations have different organizational or structural networks. It is more likely, however, that their legal consultants recognized provisions in the law such as OHCA and the business associates concept that permit organizations to share forms and / or policies. Given the limited information that we collected, we cannot really tease out which variable played the larger role, but such an exercise would be an interesting topic of follow-up research.

The structure of the interview guide places the initial question about general barriers to collaborative formation before any questions about patient confidentiality. The fact that the sharing of patient information sharing only arose spontaneously in only one interview seems to suggest that many of the respondents do not view patient confidentiality as an obstacle to forming a collaborative network among safety net providers. Many of the respondents in

our interviews were often very aware of the federal laws protecting confidentiality, but were completely unfamiliar with specific state laws. Collaborations may either assume (1) that compliance with federal law equates to compliance with state or (2) that federal law always preempts state law. However, as we noted in the introduction, federal and state laws may be quite different and require different policies and procedures for compliance. In addition, there are few state laws which are actually preempted by the HIPAA Privacy Rule. Although, several of the respondents interviewed for this project were unaware of the existence of state confidentiality laws, their organizations and collaborations are still responsible for complying with the state legislature. Take together, these findings raise the question of whether it is necessary for organizations to have prior knowledge or direct awareness of the state confidentiality laws. Since state laws may differ from the federal standard, collaborations who are unaware of state requirements and do not seek state legal assistance may be at risk.

Our findings seem to suggest that modalities for addressing confidentiality will be the same regardless of the level of knowledge about state confidentiality laws. Both the collaborations who used legal assistance and those who did not, used some type of consent form or medical release of records form to share patient information. Thus, perhaps it is not important for safety net organizations to have a direct working knowledge of state confidentiality regulations. However, if organizations are not well versed in confidentiality laws, it will be beneficial to have a legal representative review any forms they do intend to use to insure that the forms will meet both federal and state regulations.

The case studies presented here provide a list of many other barriers to collaboration between safety net providers beyond those of patient confidentiality. The importance of some of these, such as resource limitation and



physician recruitment is supported by other literature<sup>11</sup>. In fact, of the barriers listed, these two along with medications were the only barriers mentioned by multiple collaboration sites with other obstacles appearing to be unique to the individual collaborations. These findings suggest two things. On the one hand, all communities who are attempting to develop any type of collaboration may need to take careful consideration of available resources, physician/provider recruitment, and possible medication provisions. On the other hand, communities should also be aware of barriers that may be specific to a particular type of collaboration or within a particular community demographic.

In this increasingly electronic age, another consideration for community collaborations is how state and federal confidentiality laws will affect the use of electronic medical records. None of the collaborations in our project were using electronic medical records but one respondent, representing Community A said that the collaboration is attempting to develop an electronic medical record. At this point, Community A is using legal assistance to develop consent forms associated with the use of the electronic medical record that will comply with both federal and state laws where applicable. As the health environment becomes more complex it will be more important than ever to seek guidance in deciphering the equally complex laws that govern patient confidentiality.

This project provided an opportunity to collect information on collaborative networks in North Carolina. Abundant literature addresses the need for patient confidentiality and compliance with the HIPAA privacy rule; however, as we previously noted, limited published literature specifically addresses confidentiality as a barrier to health care safety net collaboration models. In addition, there is a significant lack of information specifically concerning NC confidentiality law and its integration with HIPAA. With so little published research on which to draw, it is

difficult to know how generalizable these findings are. This project was not originally designed for the specific purpose of assessing the affect of patient confidentiality protections on collaborative networks. The project was, instead, designed to develop a broad picture of North Carolina safety net collaborations, and that larger goal is reflected in the structure of the interview and its questions. The data that we collected on confidentiality are very limited and likely barely scratch the surface of confidentiality. Follow-up projects should delve more deeply into the process by which consent and medical release of records forms were designed.

This paper includes a very small sample of the communities in North Carolina, and we only analyzed a small sub-sample of representatives from the chosen collaborations. Thus, the data really only reflect the perceptions of a few key stakeholders who are involved in the collaborations. Future projects may include a larger number of safety net collaborations as well as a larger sample of respondents from each collaborative network. Researchers should also take care that respondents involved in the interview process are individuals who were directly involved in discussion and decisions regarding patient confidentiality and the formation of any documents that may be used, including persons from the safety net organization and any legal personnel who were recruited to assist.

As more safety net collaborations develop, we will have less need to investigate barriers to collaborative formation. Instead, to continue to improve the care provided to uninsured populations, we will need to move beyond examinations of collaborative initiation; to turn to evaluations of the collaborative networks' challenges as they try to serve their communities. Having understood possible barriers to the initial formation of networks, we can prepare in advance

to address the barriers – such as sustainability of the networks they have built – these collaboratives will face in the future. .

### **Acknowledgments**

I would like to thank the North Carolina Institute of Medicine for allowing me to participate in this project. In addition, I would like to thank Sue-Tolleson Rhinehart and Pam Silberman for their assistance throughout the entire project.

## Appendix A

**NC SAFETY NET COMMUNITY COLLABORATION  
CONSENT SCRIPT  
(Including Script to Obtain Permission for Name of Knowledgeable  
Individual)  
IRB Study # 05-2778**

Hello, my name is \_\_\_\_\_. I am a (student/staff member) from the North Carolina Institute of Medicine. We are conducting case studies about community collaborations to expand care to the uninsured. This study is an outgrowth of a NC IOM Safety Net Task Force that explored ways to expand the healthcare safety net to serve more uninsured.

The Task Force found that few North Carolina communities were able to address all the healthcare needs of the uninsured. Many communities have fragmented systems of care, due—in part—to the difficulties in creating community collaborations. Some of the counties that had the greatest success in serving the uninsured were those that developed partnerships across institutions. We are trying to collect information about these successful community collaborations, so that they can be shared as possible models with other communities across the state.

We understand that your organization is involved in a community collaboration in \_\_\_\_\_ county to serve the uninsured. Is this correct? *(Yes/No). If No, thank them for their time and end the call).* If yes, We are looking for a knowledgeable person in your organization that could answer some questions about the community collaboration.

Is that you? *Yes/No. If yes, state:* Your participation in this study is completely voluntary. That means you do not have to participate in this survey unless you want to. **I would like to email you a fact sheet that describes the study in more detail. Could you please give me your email mail address so that I can email you the fact sheet?** *(Alternatively, ask for a fax number if no email address).*

*Send the fact sheet and then wait for them to read it (or call back).*

Now that you have read the fact sheet, would you be willing to answer some questions to help me understand the collaborations and partnerships that exist in your community to serve the uninsured. *(If yes, proceed; if not, thank them for their time and end the call).* The interview should last about one hour. Would this be a good time to talk, or would you like to schedule another time.

*If Director of the organization is not the appropriate person, state the following:*  
Before giving me the name of this person, could you please contact them to find out if they would be willing to let you release their name to us. We will then send them a fact sheet that describes the study in more detail and will seek their permission to participate in the study.

*Once we have the name of the appropriate person, repeat introductory section that describes the study. Then read the following:*

Your participation in this study is completely voluntary. That means you do not have to participate in this survey unless you want to. I would like to email you a fact sheet that describes the study in more detail. **Could you please give me your email mail address so that I can email you the fact sheet? (Alternatively, ask for a fax number if no email address).**

*Send the fact sheet and then wait for them to read it (or call back).*

Now that you have read the fact sheet, would you be willing to answer some questions to help me understand the collaborations and partnerships that exist in your community to serve the uninsured. *(If yes, proceed; if not, thank them for their time and end the call).* The interview should last about one hour. Would this be a good time to talk, or would you like to schedule another time.

## **Appendix B**

### **HEALTHCARE SAFETY NET ORGANIZATIONS IN NORTH CAROLINA COMMUNITY COLLABORATIONS**

#### *Who is conducting the study?*

The NC Institute of Medicine (NC IOM), in conjunction with a Safety Net Advisory Council (SNAC)<sup>1</sup>, is collecting information about safety net organizations that provide healthcare services to the uninsured. This is an outgrowth of the NC IOM Safety Net Task Force, which developed ideas to strengthen community collaborations in order to expand and strengthen the capacity of safety-net providers to serve the uninsured.

(<http://www.nciom.org/projects/SafetyNet/safetynetreport.html>)

#### *What is the purpose of the research study?*

The purpose of the study is to obtain background information about successful North Carolina community collaborations that have been created to provide healthcare services to the uninsured. The NC IOM Task Force found that few North Carolina communities were able to address all the healthcare needs of the uninsured. Many communities have fragmented systems of care, due—in part—to the difficulties in creating community collaborations. Some of the counties that had the most success serving the uninsured were those that developed collaborations and partnerships across institutions. We are trying to collect information about these successful community collaborations, so that they can be shared as possible models with other communities across the state.

#### *Who are the participants of the study and how will the study be conducted?*

The participants include representatives of local safety net organizations that are working together in a particular community to expand services to the uninsured. This will vary across communities, but may include representatives of community and migrant health centers, free clinics, local health departments, state-funded rural health clinics, hospital outpatient clinics, Project Access sites, Healthy

Community Access Programs (HCAP), and other nonprofit organizations that provide healthcare services to the uninsured.

*What does participation in the study mean?*

The interview should take no longer than one-hour to complete. After we compile a description of the community collaboration from you and other collaborating partners, we will send the summary to each organization to review. Participation is completely voluntary. You do not need to answer any questions that you do not wish to answer.

*What are the possible benefits from participating in this survey?*

The goal of these case studies is to help other communities develop or strengthen collaborative efforts to extend care to the uninsured. There is no direct benefit to individual subjects who participate in the study, although it may be beneficial to your organization by informing the public about collaborations and services that you provide. There is no payment for participation.

Whether or not you choose to participate in this study will not affect your organization's reputation or future dealings with the NC Institute of Medicine.

*What are the possible risks or costs involved from participating in this survey?*

There are negligible risks of participation in this survey. There are no costs involved in participating in the study, other than the time it takes to complete the survey.

*For more information about this study:*

If you have any questions or want more information about this project, you can contact: Pam Silberman, JD, DrPH, President and CEO, North Carolina Institute of Medicine ([pam\\_silberman@unc.edu](mailto:pam_silberman@unc.edu)) or Kristen Dubay, MPP, Project Manager ([Kristen\\_dubay@nciom.org](mailto:Kristen_dubay@nciom.org)), or you can contact the NC Institute of Medicine at 919-401-6599.

All research on human volunteers is reviewed by a committee that works to protect your rights and welfare. If you have any questions or concerns about your rights as a research subject, you may contact, anonymously if you wish, the Institutional Review Board at 919-966-3113 or by email to [IRB\\_subjects@unc.edu](mailto:IRB_subjects@unc.edu) (IRB #05-2778).

<sup>i</sup> The SNAC is comprised of representatives of the NC Office of Research, Demonstrations and Rural Health Development and the Division of Public Health (DPH) within the NC Department of Health and Human Services, the NC Area Health Education Centers program (AHEC), the NC Hospital Association (NCHA), the NC Medical Society (NCMS), the NC Community Health Center Association (NCCHCA), the NC Association of Free Clinics (NCAFC), state-funded rural health clinics, local community health centers, local health departments, and Project Access administrators.

## Appendix C

### COMMUNITY COLLABORATIONS SEMI-STRUCTURED INTERVIEW GUIDE DRAFT

1. Site:
2. Respondent's name and title: \_\_\_\_\_

**First, I'd like you to give us a little background on the community collaboration**

3. Can you tell us a little about the history of the community collaboration?
  - a. Briefly describe the collaboration
  - b. When did it start?
  - c. How did it develop? (*Probe: Did it grow out of another initiative? Was it the brainchild of a particular individual or organization? Who took the leadership?*)
  - d. Where is the collaboration housed?
4. What are the other collaborating organizations in this effort (i.e., community health center, local health department, mental health, hospital, free clinic, other community providers)?
  - a. What does each of the collaborating partners do? (*Probe: donate services or staff, provide financial or other support, part of a referral network, other?*)
  - b. Who are the key organizational partners in this collaboration?
5. What services are provided in the collaboration, and by whom? (*for example: Primary care, specialty, ancillary (lab & xray), hospital services (in and/or outpatient), dental, mental health and substance abuse, pharmacy, enabling services (if so, what)*)
  - a. Are these services provided for free or on a sliding fee scale to low-income uninsured?
6. How many patients does the collaboration see in a year?
  - a. What percentage is uninsured? Medicaid/NC Health Choice? Medicare? Private insurance?
  - b. Age composition of the patient population
  - c. Racial and ethnic breakdown (including percentage who are Latino)
  - d. What percentage have limited English proficiency (i.e., need interpreter services)
  - e. If there are multiple organizations involved in the collaboration, what percentage and types of patients are being seen in different collaborating organizations (for example, does the health department see certain types of patients, and the free clinic see others)?

7. Do you have eligibility criteria to qualify for services? If so, what is the maximum income a person can make?
8. Do you have a sliding scale fee?
  - a. If so, what is the minimum payment? How is the sliding scale fee structure
9. For systems that rely on donated services...
  - a. How many providers are donating their time? (what types)
  - b. Do you keep data on the value of the donated services?
  - c. What percentage of the uninsured patients is seen by traditional safety-net providers (i.e., CHCs, health departments), what percentage is being seen by free clinics with volunteer providers, and what percentage are being seen by private physicians/providers?
10. Do you provide case management or disease management?
  - a. If so, is it targeted to specific health conditions or types of patients?

**Now, I'd like you to focus on the barriers to the collaboration, and how you overcame them (if any)**

11. Barriers and Facilitators to Integration/Collaboration:
  - a. Over the history of the collaboration, did you have any barriers to collaboration that you needed to overcome? (*Probe: trust issues, confidentiality of records, competition for finances, competition for patients, etc.*) If so, how did you overcome these barriers?
  - b. Do you share patient records across organizations? If so, how do you address patient confidentiality issues? (*Probe: Do you get signed releases? Are you part of the same healthcare system? Other?*)
  - c. What do you think has helped your collaboration succeed? Please describe what factors helped make your collaboration a success?
  - d. Do you think that your collaboration could be duplicated elsewhere, or is it unique to your community?
12. If you were going to give lessons to people in other communities that wanted to start a similar safety net community collaboration, what are the most important lessons for them to know?

**Finally, I'd like a little information about outcomes of the community collaboration:**

13. Did this collaboration increase the number of underserved individuals served by the different collaborating partners, expand services provided, or otherwise expand the capacity of the individual organizations to serve the uninsured or other underserved populations? If so, how?
14. Do you collect data on health status, process measures or health outcomes?
  - a. Hospitalizations and/or use of emergency room
  - b. Certain clinical indicators (i.e., eye exams for diabetics)
  - c. Self-reported health status (i.e., SF-12 forms)



- d. Other
  - e. If yes, what are the results (and can you get a copy of any reports)
15. Do you collect data on patient satisfaction?
- a. If so, what are the results of the most recent patient satisfaction survey
16. Do you collect data on other outcomes (e.g., return on investment, lost productivity of enrollees, etc.)

## **Appendix D – Case Summaries**

### **Community A**

Project Access began around 1996 with the primary goal of providing access to health care for uninsured residents of the county who are at or below 200% of the federal poverty guideline (FPG). The project is funded by the Robert Wood Johnson Foundation as well as local county commissioners. Project Access is led by the county Medical Society (MS) and includes over 100 volunteers who represent the county's health and social service agencies, businesses, elected officials, private physicians and medical under-served communities.<sup>22</sup>

Through Project Access physicians and community partners donate their services to patients with little or no reimbursement or compensation. Primary care, specialty care and some labs and x-rays are provided by the safety net clinics and private physicians. The hospital provides inpatient care as well as some labs and x-rays and a few local dentists provide dental care. There are some community psychiatrists who provide mental health services, though some Project Access enrollees are referred to some nonprofit community programs staffed by counselors or other community behavioral health programs. Project Access also provides pharmacy services by allotting a set amount of money (\$750) per year per enrollee to assist with medications. The patient is required to pay a \$10 co-pay. They also help patients enroll into Medication Assistance

Programs through the pharmaceutical companies. In addition, they recently developed an interpreter network composed of volunteer interpreters who can be used by Project Access enrollees. Thus, Project Access provides a full continuum of care for the low income uninsured patients.

The planning process for Project Access began in the fall of 1994 and lasted until the fall 1995. In November 1995 through April 1996, they were actively seeking participation pledges from physicians. They began enrolling patients in April 1996 and now see about 300 patients each year. Case workers from the Department of Social Services (DSS) screen all potential patients for eligibility for other insurance (e.g., Medicaid, Medicare) before being enrolled. All Project Access clients must be uninsured and have incomes less than or equal to 175% of the federal poverty guidelines. There is no fee to participate in Project Access though some participating clinics may use a sliding scale and participants have a co-pay for medications. All specialty and hospital services are provided free of charge to patients. Patients present their Project Access card to physician offices, similar to an insurance card. This also allows physicians to submit a claim to the Project Access office so that they can keep track of the monetary value of all donated services.

Project Access cares for about 3000 patients each year. In general, patients are between 19 and 65 years old because NC Health choice covers children less than 18 years old and Medicare covers adults over 65. The racial and ethnic breakdown of Project Access patients essentially reflects that of the surrounding community: approximately 8% African American, 15% Latino, a few Asians and Native Americans and the remainder are Caucasian. Approximately 12-15% of the Latino population and a large number of Russian / Ukrainians in the area require the translator services.

Project Access has seen many changes and improvements in the surrounding community. Safety net clinics are now able to make referrals easily for patients, thereby preventing patients from having to return several times before seeing a specialist. This frees up appointment slots in the safety net clinics and allows the providers to see more uninsured patients. In addition, wait time for patient appointment at the safety net clinics is down from about 1-2 weeks to within a few days. Project Access has also helped expand the safety net capacity from the original three safety net clinics to currently five or six. The project really allows the safety net to give community standard of care to its participating uninsured patients.

### **Community B**

The Community Care Plan (CCP), Inc. is a not-for-profit 501C-3 corporation, with multiple community partners dedicated to the provision of healthcare for Medicaid recipients and the uninsured population via the Carolina Access III Plan and Community Care Plan respectively. The Carolina Access III portion of the CCP manages the Medicaid recipients in the County while the Community Care Plan addresses health care for the uninsured and underinsured in the community<sup>23</sup>. The Community Care Plan was integrated with the existing Carolina Access III Medicaid managed care program to increase the community's safety net provider and support services to assure quality, effective and efficient management of the uninsured with the community. In addition, this allowed the program to utilize the existing resources and avoid duplicating existing structure.

There are many organizations involved in the collaboration, including NorthEast Medical Center, the Health Alliance, the County Department of Social Services, The Community Free Clinic, the College of Health Sciences, County Transportation Services, the local Family Medicine Residency Program,

Cooperatives Christian Ministry, Dental Care Access Task Force, Latino Advocacy Council of the county, Local physicians and NorthEast Medical Center Medical Staff, North Carolina Office of Research and Demonstrations, and Rural Health Development, and Piedmont Behavioral Healthcare. Each partner is an integral part of the Community Care Plan and contributes by donating time or services to the collaborative effort to serve the uninsured. Together, they provide comprehensive medical care for adults and children, behavior health services, transportation for medical visits, translation services and in some cases food, clothing and emergency resource funds for participants.

The majority of medical providers in the County are participating in the CCP. Each medical provider agrees to see a pre-selected number or percentage of patients when they join the CCP. If a health care provider has reached his / her cut-off, then patients are sent to another provider with openings for CCP patients. Providers submit a paper claim to the CCP that allows the plan to keep track of the financial value of the donated medical services. As of August 2005, the Community Care Plan had received services equal to \$3.3 million from the hospital, \$1.7 million from primary care providers and \$900,000 from specialty providers.

The Community Care Plan began enrolling indigent patients in February 2002. All patients are initially assessed at the Department of Social Services. If individuals are not eligible for public programs then they can be enrolled in the Community Care plan. Participants must be uninsured, residents of the county, and have an income below 125% of the federal poverty guideline. After participants are enrolled in CCP, they are able to receive comprehensive health care services with no cost to the individual. Each participant is assigned a primary care home with one of the participating community providers and

receives an identification card with the provider's name. The ID card operates much like an insurance card when presented at the provider's office at the time of health care visits. The CCP also provides case management for patients with asthma or diabetes and for patients who appear to have difficulties with medical compliance.

The Community Care Plan serves approximately 1,200 patients yearly. Participants are reassessed for eligibility every 6 months and those who do not return for the reassessment are dropped from the program. As of January 2006, 1,320 active participants were enrolled and CCP had served 6,064 participants over last 4 years. CCP members range between ages 0-65 with the majority between 19-55 years old. In general, about 70% of CCP participants are female and 30% male. The racial and ethnic breakdown is as follows: 42% Latino / Hispanic, 29% Caucasian, 22% African-American and 6% other groups.

The Community Care Plan has been successful in a variety of ways – some of which are measurable. Since its inception, CCP has seen a decrease in emergency room visits by its members such that ER visits now account for less than 3% of total donated care. Much of this was accomplished as CCP targeted interventions toward conditions that were causing patients to go to the ER for care.

### **Community C**

Family Health Services (FHS) was created by the county Health Department to help provide comprehensive medical care to indigent citizens. It was developed as a non-profit organization to provide primary care health care for indigent patients. From this beginning, a collaborative developed between FHS and the county Health Department (CHD) with a common goal to insure that the county safety net remained intact. Together, they provide primary care for

adults, children, and special populations (HIV+, mentally ill); pediatric and adult dental services; hospital care; reproductive health, immunizations; behavioral health / case management and access to specialty providers.

The county collaboration developed in 1989 and unlike many other community collaborations only consists of the FHS and CHD. Both FHS and the CHD are housed under the same roof at the health department and can share many of the same resources such as health and billing staff. Sharing resources allows the collaboration to provide comprehensive health care to the uninsured, low-income community without duplicating services. The Health Department primarily provides primary care in pediatrics and maternity care, serving women and children. Family Health Services tries to fill in the gaps and provide primary care, acute care, and treatment for communicable diseases in populations who do not receive care at the Health Department.

Both FHS and CHD have physicians on staff to care for patients. In addition, FHS has volunteer clinics that are driven by specialists such as ophthalmologists and podiatrists as well as volunteers who work on pharmaceutical medication assistance programs for the patients. Although there are no data on the value of donated services, volunteer hours are documented. Case management is also provided and primarily targeted to patients with chronic diseases or who are HIV positive.

Together, the County collaboration sees about 78,000 patients annually – 60,000 through the Health Department and 18,000 through FHS. 55% of the patients seen at FHS are uninsured while the remaining 45% is divided between Medicaid (22%), Medicare (5%) and private insurance (5%.) The bulk of HD patients are seen in either the family, child health, or maternity clinic, making for a patient population mostly aged 0-45 years, although the clinics do see some

elderly patients. FHS generally has a broader age span of patients ranging from 6 months until death with 57% Caucasian, 35% African American, and 8% Latino. The racial / ethnic breakdown at the Health department will vary depending on the clinic that is sampled. At both clinics, much of the Latino patient population requires an interpreter for service.

There are no eligibility criteria for patients desiring to be seen by FHS or the CHD; however, for some specific HD questions, patients must reside within the county lines. Both FHS and CHD use a sliding fee scale although some services at the health department are provided for free. At FHS, there is a minimum payment of \$15 while the health department slides down to zero. Incomes greater than 200% of the federal poverty guideline (FPG) are required to pay normal fees however, at 125-150% FPG, patients are responsible for 40% of their bill; at 100-125% FPG, patients pay 20%, etc.

Since its inception, this Gaston County Safety Net collaboration has provided care for many patients. Unfortunately, it is difficult to track utilization for the uninsured patients who are seen through the collaboration. However, Community Care of North Carolina is able to keep track of services and utilization for Medicaid patients, making it a potentially useful proxy for the entire population. With the local economic decline and the influx of Latinos, the demand for services has increased. Recent patient satisfaction surveys reveal that over 90% of patients are pleased with the service that they receive at either the Health Department or FHS.

### **Community D**

The Community Health Network (CHN) of this county is a subgroup of the Partnership for Health Collaborative existing between the health and social service providers in the county. The mission of Partnership for Health is to

collaborate for the health of the county by developing health programs throughout the region. The Community Health Network is the only program affiliated with Partnership for Health that works directly with patients. They receive fiscal support from Partnership for Health and share eleven partners with CHN.

The Community Health Network developed when the Health Resources and Service Administration (HRSA) began allocating money for local communities to coordinate care for the uninsured. Several leaders within the county came together to develop a plan of action to care for the uninsured in the area. In 2004, they received a grant from the Healthy Communities Access Program, from HRSA, to implement a program within the local community. The initiative covers three bordering counties. As a starting point, they developed five overarching goals to improve health care for the uninsured in the community. The first was to develop an internet tracking system or database to enable the safety net providers to track health care utilization by uninsured in the community. The second goal was to give health care providers a standardized disease management protocol for common health conditions. CHN supplements this by providing case managers to patients with specific medical conditions to aid the patient with navigating the health care system so that they can best manage their condition without resorting to excess emergency room use. The third goal was to improve available care for mental health conditions. One method to accomplish this is by integrating mental health into primary care practices. The fourth goal was to focus on improving health services provided to the Latino / Hispanic populations within the community. CHN has provided bilingual staff in clinics to assist with health care and currently have bilingual staff at 30-40% of the clinics. The final task was to improve access to medications by



developing a community pharmacy where patients are able to receive medications for free or low cost. This pharmacy became fully operational in November 2005.

The Community Health Network does not provide direct medical care. Rather, it helps patients navigate the health care system and effectively utilize the services already existing in the community. It accomplishes this in several ways. CHN partners with several organizations and providers in the community who agree to be a part of the collaboration and provide services for clients who enroll in CHN. There is a large mix of partners and service providers who participate, including: the local hospital, the local family medicine residency program, private community physicians, Saluda Medical Center, Free clinics, FQHC, Case Management Agencies, DSS, the Office of Rural Health & Information Management Systems, Faith based agencies, and a Quality Improvement Agency. In addition, CHN provides limited direct patient services through the sliding scale pharmacy and case management for clients with depression, asthma or diabetes. CHN also contracts with community therapists for services at reduced rates. The mental health services are free for CHN patients.

Since its inception, CHN has enrolled between 700 and 1000 clients throughout Henderson, Polk, and Transylvania counties. Applicants must be uninsured, earn below 200% of the federal poverty guideline and live in the catchment's area of one of the three counties. Once they are approved, clients receive a CHN card that functions much like an insurance card. The card permits providers to issue a 'dummy' bill for all services and allows the collaboration to track health care utilization and assess the monetary value of all services provided. CHN clients range between 18-64 years old and are primarily

Caucasian (64%) although other racial/ethnic groups also participate (32% Latino, 4% African American). The majority (48%) of CHN clients are seen by private physicians for health care services. Those remaining receive care from the HD (13%) of the FQHC (39%).

CHN completed its first audit in March 2006. It collected data on a variety of measures including hospitalizations and ER use; clinical indicators such as diabetic foot exams; health status and other health outcomes; administrative outcomes such as people served; provider satisfaction; case management encounters; outreach activities; cost savings and other process measures. Though the official analysis is not yet available, a few interesting trends have emerged. Hospital reports indicate that there has been a decrease in emergency room use since CHN began. In just three months, the community pharmacy has dispensed over \$40,000 worth of medications to 242 patients. Many CHN clients did not have primary care physicians and often had no knowledge of how to navigate the health care system. After enrolling in the network, people were connected to a physician and better equipped to manage their health. The Community Health Network has expanded access to medical care and assisted people in finding medical homes.

## Appendix E – Example of Shared Consent Form

CLIENT AUTHORIZATION TO RELEASE AND SHARE INFORMATION COMMUNITY HEALTH NETWORK (CHN)	
<b>CLIENT INFORMATION</b>	
This authorization is for the release and sharing of my individual identifiable information which includes: participation in an Agency program, demographic information to include name, birth date, gender, race, social security number, address, phone number, family members, financial information, employment status, residential, health and treatment history, and/or personal or family needs information.	
CLIENT'S NAME _____	
ADDRESS _____	
BIRTHDATE _____ DAYTIME TELEPHONE NUMBER _____ SOCIAL SECURITY NO. _____	
<b>DEFINITION OF CHN:</b>	
CHN is a network of providers who access a shared client information system (Case Management Information System - CMIS) that was modified jointly by Partnership for Health, Inc. (PFH), 5 Rivers Systems, and the NC Foundation for Advanced Health Programs and Office of Development and Rural Health. CMIS electronically links health care providers and human services agencies in a three county area in western North Carolina (collectively the "Network Agencies or individually "Network Agency") to share client protected information to better serve clients, reducing duplication of efforts and services among various social service agencies and health care providers, and to decrease gaps in access to services for low-income people in Hendersonville-Brevard-Saluda area. The CMIS shared electronic database provides access to resource information used to quickly assist low-income people in finding healthcare, medications, and other basic human needs.	
<b>PURPOSE OF RELEASE AND SHARING OF INFORMATION:</b>	
The purpose of this Authorization Form is to allow staff of the CHN Member Agencies to better meet my needs, and the needs of any minors for which I am responsible, through coordinated service identification, planning and delivery.	
<b>PROTECTION OF INFORMATION TO BE SHARED:</b>	
We protect the information in CHN by strictly limiting who can enter and read the information. We require all Network Agencies and Network Agency authorized staff members to sign confidentiality agreements to maintain the security of your information.	
<b>AUTHORIZATION TO RELEASE AND SHARE INFORMATION:</b>	
I hereby give my consent for my information to be entered into the CHN electronic database and shared with Network Agencies to be used for my care coordination, treatment and service delivery evaluation. A list of Network Agencies is available to me upon my request. My information will remain confidential and will not be used for marketing or solicitation purposes - or shared with any individuals or agencies outside of CHN - without additional written authorization from me. I understand that I can refuse access to part or all of my information, and may limit the access to certain Network Agencies, at any time, by a written statement. If I choose not to give my consent, my refusal will not prevent me from receiving healthcare services from a CHN Network Agency (Physician, Hospital). CHN Network Agencies have the right to deny non-healthcare services based on their individual policies and procedures (Social Service Agencies). CHN reserves the right to add agencies from time to time to provide me with more opportunities for assistance. I hereby authorize the release and sharing of my individually identifiable information. I understand that this authorization will expire one (1) years from the date of signature below.	
<b>RELEASE FROM LIABILITY:</b>	
I HEREBY RELEASE PARTNERSHIP FOR HEALTH, 5 RIVERS SYSTEMS, AND THE NC ADVANCED HEALTH PROGRAMS AND ALL OTHER NETWORK AGENCIES THAT PARTICIPATE NOW OR IN THE FUTURE, FROM ANY AND ALL LEGAL LIABILITY THAT MAY ARISE FROM THE DISCLOSURE OF MY INFORMATION.	
ALCOHOL/DRUG/INFECTIOUS DISEASE/MENTAL HEALTH RECORDS are protected by Federal Regulation 42 CFR, Part 2. Release of such records requires specific consent. I hereby grant such specific consent as initialed below. I UNDERSTAND that these records are protected under federal and state law and cannot be disclosed without my written consent unless otherwise provided by law. I further understand that the specific type of information to be disclosed may, if applicable, include diagnosis, prognosis, and treatment for physical and/or mental illness including treatment of alcohol or substance abuse, sexually transmitted diseases, acquired immune deficiency syndrome (AIDS), or human immunodeficiency virus (HIV) infection.	
AS PART OF THE MEDICAL RECORDS CHECKED ABOVE, THE FOLLOWING INFORMATION WILL BE RELEASED UNLESS CROSSED-OUT:	
HIV/AIDS related information and/or records	Mental Health information and/or records
Sexually transmitted diseases	Drug/alcohol diagnosis, treatment or referral information
SIGNATURE: _____	DATE: _____
<small>Client or legal representative</small>	
<b>AGENCY RESTRICTION:</b>	
I understand that restricting release and sharing of my information may limit the ability of the Network Agencies to provide care coordination and treatment for me or any minors for which I am responsible. I do not authorize the sharing of my information with the following agencies: _____	
<b>RIGHT TO REVOKE AUTHORIZATION:</b>	
I MAY REVOKE THIS AUTHORIZATION AT ANY TIME, IN WRITING, BEFORE THE INFORMATION HAS BEEN RELEASED. I FURTHER UNDERSTAND THAT I HAVE A RIGHT TO RECEIVE A COPY OF THIS AUTHORIZATION UPON REQUEST.	
<b>SIGNATURE:</b>	
BY SIGNING THIS AGREEMENT, I ACKNOWLEDGE THAT I HAVE CAREFULLY READ, UNDERSTAND AND AGREE TO THE ABOVE TERMS AND CONDITIONS.	
Client Signature: _____	Date: _____ Parent,
Guardian or Legal Representative Signature: _____	
Printed Name of Parent, Guardian or Legal Representative: _____	
Relationship to Client: _____	

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